Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

NATIONAL GUIDELINE CLEARINGHOUSE

General

Guideline Title

Developmental follow-up of children and young people born preterm.

Bibliographic Source(s)

National Guideline Alliance. Developmental follow-up of children and young people born preterm. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. 29 p. (NICE guideline; no. 72).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

NEATS Assessment

National Guideline Clearinghouse (NGC) has assessed this guideline's adherence to standards of trustworthiness, derived from the Institute of Medicine's report Clinical Practice Guidelines We Can Trust.

= Poor = Fair = Good = Very Good = Excellent

Assessment	Standard of Trustworthiness
YES	Disclosure of Guideline Funding Source
	Disclosure and Management of Financial Conflict of Interests
	Guideline Development Group Composition
YES	Multidisciplinary Group
YES	Methodologist Involvement

▮▮▮▮▯	Patient and Public Perspectives
	Use of a Systematic Review of Evidence
▮▮▮▮▮	Search Strategy
▮▮▮▮▮	Study Selection
▮▮▮▮▮	Synthesis of Evidence
	Evidence Foundations for and Rating Strength of Recommendations
▮▮▮▮▯	Grading the Quality or Strength of Evidence
▮▮▮▮▮	Benefits and Harms of Recommendations
▮▮▮▮▮	Evidence Summary Supporting Recommendations
▮▮▮▯▯	Rating the Strength of Recommendations
▮▮▮▮▯	**Specific and Unambiguous Articulation of Recommendations**
▮▮▮▮▮	**External Review**
▮▮▮▮▮	**Updating**

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Information and Support for Parents and Carers of All Preterm Babies

Providing Information and Support

Be aware that the majority of children and young people born preterm have a good developmental outcome and good quality of life.

Provide information about the risk and prevalence of developmental problems and disorders in babies born preterm (see "Risk and Prevalence of Developmental Problems and Disorders" below) to parents or carers, and offer to discuss this with them.

Provide information to parents or carers of preterm babies that is tailored to their individual circumstances, taking into account:

- Their child's potential developmental needs
- Their level of education
- Any social care needs they have

Any cultural, spiritual or religious beliefs
The need for consistency in information sharing among healthcare professionals.

Follow the principles in the NICE guideline on patient experience in adult NHS services in relation to communication (including different formats and languages), information, shared decision-making and continuity of care.

Provide emotional and psychological support to parents or carers of preterm babies as needed, recognising the significant potential impact of having a preterm baby on all the family. Times when support may be particularly valuable include:

When the baby is transferred between units or hospitals
Leading up to and on discharge home.

Provide information to parents or carers of preterm babies about opportunities for peer support.

Information and Support Leading up to and on Discharge Home

Discharge Planning and Support

Start discharge planning as soon as possible after the birth of a preterm baby, and involve parents or carers at all stages.

Before discharging a preterm baby:

Agree a discharge plan with the parents or carers
Ensure that the discharge plan includes clear information about any antenatal and perinatal risk factors for developmental problems and disorders (see "Risk and Prevalence of Developmental Problems and Disorders" below)
Share the written discharge plan with parents or carers and with primary and secondary healthcare teams.

Help parents or carers to gain the knowledge, skills and confidence they need to look after their baby at home and to support the baby's developmental needs, taking into account that they are likely to be anxious about caring for their baby after discharge. This may relate to:

Interaction with the baby
Managing feeding
Patterns of sleeping
Physical positioning of the baby, including safe sleeping
Impact on day-to-day living, such as social isolation because of fear of infection.

Involve the social support networks (which may include partners, grandparents or other family members) of parents or carers of a baby born preterm when planning discharge and during follow-up.

Information Before Discharge About Ongoing Support and Follow-up

Inform parents or carers of all preterm babies about the routine postnatal care and support available, as described in the NICE guideline on postnatal care up to 8 weeks after birth.

Explain to parents and carers of preterm babies about:

Universal services and national recommendations for assessing the development of all children through screening (for example, newborn hearing screening) and surveillance (including social, emotional, behavioural and language development) (At the time of publication [August 2017], these universal screening and surveillance services are delivered through the Healthy Child Programme in England) and
Whether their baby will also be offered enhanced developmental support and surveillance (see "Enhanced Developmental Support and Surveillance" below) and plans for follow-up.

Explain to parents or carers that their child's developmental (corrected) age, which is calculated from their original due date (and not the date they were born), will be used for the first 2 years when assessing their functional and developmental skills (such as walking and talking).

Advise parents or carers to talk to their health visitor or general practitioner (GP) if they have any concerns about their child's development at any stage of childhood or adolescence.

Care, Support and Follow-up after Discharge

Healthcare professionals providing postnatal care and support in the community for babies born preterm should have the skills and knowledge to recognise and manage problems in these babies, including:

- Providing feeding support
- Addressing concerns about sleeping
- Helping parents or carers to interact with their baby.

Risk and Prevalence of Developmental Problems and Disorders

Be aware that children and young people born preterm are at increased risk of developmental problems and disorders.

Be aware that for recommendations in this section:

- For some developmental problems and disorders there was an absence of evidence about overall risk and prevalence in children born preterm
- There was limited evidence about developmental problems and disorders in 11- to 18-year-olds
- For some developmental problems and disorders the evidence was underpowered to detect an effect
- Some studies described specific gestational ages at birth, from which the committee was unable to extrapolate to other gestational ages
- Other gestational ages and other factors not listed here might also be associated with increased risk of developmental problems and disorders.

Cerebral Palsy

Be aware that children born preterm are at increased risk of cerebral palsy, and that:

- The following are independent risk factors:
  - Grade 3 or 4 intraventricular haemorrhage
  - Cystic periventricular leukomalacia
  - Neonatal sepsis
  - Bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age
  - Antenatal steroids not given
  - Postnatal steroids given to babies born before 32^{+0} weeks' gestation
- Prevalence increases with decreasing gestational age.

See also the NICE guideline on cerebral palsy in under 25s: assessment and management.

Motor Function Problems

Be aware that children born preterm are at increased risk of motor function problems, and that the following are independent risk factors:

- Brain lesions (for example, grade 3 or 4 intraventricular haemorrhage, periventricular leukomalacia, infarct)
- Necrotising enterocolitis that needed surgery
- Neonatal sepsis
- Severe retinopathy of prematurity.

Be aware that there is an increased prevalence of developmental coordination disorder in children born preterm compared with the general population.

Learning Disability (Intellectual Disability)

Be aware that children born preterm are at increased risk of learning disability (intellectual disability), and that:

- The following are independent risk factors:
  - Grade 3 or 4 intraventricular haemorrhage
  - Cystic periventricular leukomalacia
  - Neonatal sepsis in babies born before 28^{+0} weeks' gestation
  - Necrotising enterocolitis that needed surgery in babies born before 33^{+0} weeks' gestation
  - Bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age in babies born before 28^{+0} weeks' gestation
  - Severe retinopathy of prematurity in babies born before 28^{+0} weeks' gestation
  - Small for gestational age
  - Postnatal steroids given to babies born before 33^{+0} weeks' gestation
  - Mother from a low-income or disadvantaged background
- Prevalence increases with decreasing gestational age.

Special Educational Needs and Educational Attainment

Be aware that children born preterm are at increased risk of having special educational needs, and that the following are independent risk factors:

- Brain lesions detected by ultrasound
- Male sex.

Be aware that children born preterm are at increased risk of low educational attainment at the end of the Early Years Foundation stage and at key stage 1 (age up to 7 years), and that:

- Prevalence of low educational attainment increases with decreasing gestational age
- Children born preterm are at increased risk of low attainment for reading and maths, and this risk is greater in children born before 26^{+0} weeks' gestation
- The following are independent risk factors for low attainment in maths in children born before 32^{+0} weeks' gestation:
  - Intraventricular haemorrhage
  - Bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age.

Executive Function Problems

Be aware that children born before 32^{+0} weeks' gestation are at increased risk of executive function problems at preschool and school ages, and that prevalence increases with decreasing gestational age.

Speech, Language and Communication

Be aware that children born preterm are at increased risk of speech, language and communication problems and disorders, and that the following are independent risk factors for language disorder:

- Grade 3 or 4 intraventricular haemorrhage
- Cystic periventricular leukomalacia
- Male sex.

Attention, Impulsivity and Hyperactivity

Be aware that children born before 33^{+0} weeks' gestation are at increased risk of symptoms of

hyperactivity, impulsivity and particularly inattention at preschool and school ages.

Be aware that children born before 28^{+0} weeks' gestation are at increased risk of attention deficit hyperactivity disorder (ADHD), and that male sex is an independent risk factor.

Autism Spectrum Disorder

Be aware that children born before 28^{+0} weeks' gestation are at increased risk of symptoms of social communication impairment, which may suggest a problem in the autism spectrum.

Be aware that children born preterm are at increased risk of autism spectrum disorder, and that the following are independent risk factors:

- Intraventricular haemorrhage in babies born before 34^{+0} weeks' gestation
- Male sex.

Emotional and Behavioural Problems

Be aware that children born preterm are at increased risk of emotional and behavioural problems, particularly internalising behaviours and passivity, at preschool and school ages, and that the following are independent risk factors:

- Major brain lesions (for example, periventricular leukomalacia, parenchymal lesions)
- Mother with mental health problems
- Mother younger than 25 years
- Mother from a low-income or disadvantaged background.

Feeding Problems

Be aware that children born preterm are at increased risk of oro-motor feeding problems (for example, problems with sucking and chewing), and that this increased risk persists until at least 6 years of age in children born before 26^{+0} weeks' gestation.

Sleep Problems

Be aware that children born preterm are at increased risk of sleep apnoea up to 6 years of age.

Visual Impairment

Be aware that the prevalence of visual impairment increases with decreasing gestational age in children born preterm, and that the following are independent risk factors:

- Grade 3 or 4 intraventricular haemorrhage with a shunt
- Neonatal sepsis in babies born before 33^{+0} weeks' gestation
- Retinopathy of prematurity needing treatment.

Hearing Impairment

Be aware that the prevalence of hearing impairment increases with decreasing gestational age in children born preterm, and that neonatal sepsis is an independent risk factor in babies born before 28^{+0} weeks' gestation.

Developmental Delay

Be aware that children born preterm are at increased risk of developmental delay (identified using a range of tools), and that the following are independent risk factors:

- Small for gestational age
- Male sex
- Mother from a low-income or disadvantaged background

Black, Asian or other minority ethnic group
Multiple pregnancy.

Enhanced Developmental Support and Surveillance

Criteria for Enhanced Developmental Support and Surveillance up to 2 Years (Corrected Age)

Provide enhanced developmental support and surveillance by a multidisciplinary team (see "Delivering Enhanced Developmental Support and Surveillance," below) up to 2 years (corrected age) for children born preterm who:

Have a developmental problem or disorder or
Are at increased risk of developmental problems or disorders, based on the following criteria:
Born before 30^{+0} weeks' gestation or
Born between 30^{+0} and 36^{+6} weeks' gestation and has or had 1 or more of the following risk factors:
A brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
Grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
Neonatal bacterial meningitis
Herpes simplex encephalitis in the neonatal period.

Consider enhanced developmental support and surveillance by a multidisciplinary team up to 2 years (corrected age) for children born preterm who do not meet the criteria in the previous recommendation but are suspected of being at increased risk of developmental problems or disorders, taking into account the presence and severity of risk factors (see above recommendations).

Criteria for Enhanced Developmental Support and Surveillance at 4 Years (Uncorrected Age)

Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28^{+0} weeks' gestation (see "Further Developmental Assessment at 4 Years [Uncorrected Age] for Children Born Before 28^{+0} Weeks' gestation" below).

Providing Enhanced Developmental Support

Provide parents or carers of a preterm baby having enhanced developmental support with a single point of contact within the neonatal service for outreach care after discharge.

Use a range of approaches when providing enhanced developmental support and tailor the support to take account of individual preferences and needs. Approaches may include:

Face-to-face meetings, in clinics or in the home
A telephone helpline
Text messages, emails or similar.

Providing Enhanced Developmental Surveillance up to 2 Years (Corrected Age)

For all children born preterm who are having enhanced developmental surveillance, provide as a minimum:

2 face-to-face follow-up visits in the first year that focus on development, at the following corrected ages:
Between 3 and 5 months and
By 12 months
and

A detailed face-to-face developmental assessment at 2 years (corrected age) (see "Developmental Assessment at 2 Years [Corrected Age]" below).

Checks at Each Developmental Visit and Assessment

At each face-to-face follow-up visit and developmental assessment (see "Providing Enhanced Developmental Surveillance up to 2 Years [Corrected Age]," above, and "Developmental Assessment at 2 Years [Corrected Age]" and "Further Developmental Assessment at 4 Years [Uncorrected Age] for Children Born Before 28^{+0} Weeks' Gestation," below) for a child born preterm who is having enhanced developmental surveillance, professionals with appropriate skills (see "Delivering Enhanced Developmental Support and Surveillance" below) should:

- Discuss with parents or carers whether they have any concerns about their child's development
- Include checks for developmental problems and disorders (see next recommendation)
- Measure length or height, weight and head circumference
- Carefully evaluate and review any developmental concerns reported by parents or carers or noted during the visit or assessment
- Correct for gestational age up to 2 years when assessing development
- Consider further investigation or referral if a developmental problem or disorder is suspected or present
- Refer the child to the appropriate local pathway if needed.

At each face-to-face follow-up visit and developmental assessment for a child born preterm who is having enhanced developmental surveillance, check for signs and symptoms of developmental problems and disorders as appropriate, such as:

- Cerebral palsy (see recommendation below)
- Global developmental delay and learning disability (intellectual disability)
- Autism spectrum disorder (see recommendation below)
- Visual impairment
- Hearing impairment
- Feeding problems
- Sleep problems, including sleep apnoea
- Speech, language and communication problems
- Motor problems
- Problems with inattention, impulsivity or hyperactivity
- Emotional and behavioural problems
- Executive function problems
- Potential special educational needs.

Recognise the following as possible early motor signs of cerebral palsy:

- Delayed motor milestones, such as late sitting, crawling or walking (correcting for gestational age)
- Unusual (abnormal or absent) fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement
- Abnormalities of tone, including hypotonia (floppiness) or spasticity (stiffness)
- Persisting feeding difficulties.

See also the NICE guideline on cerebral palsy in under 25s: assessment and management.

For guidance on recognising signs and symptoms of possible autism spectrum disorder, see the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis.

Developmental Assessment at 2 Years (Corrected Age)

Provide a face-to-face developmental assessment at 2 years (corrected age) for children born preterm who are having enhanced developmental surveillance. This assessment should include as a minimum:

- All aspects listed in the first recommendation under "Checks at Each Developmental Visit and

Assessment," above
Using the Parent Report of Children's Abilities – Revised (PARCA-R) to identify if the child is at risk of global developmental delay, learning disability (intellectual disability) or language problems:
If the PARCA-R is not suitable (for example, because of poor English language comprehension or the child being outside the validated age range of 22 to 26 months), use a suitable alternative parent questionnaire
Gross Motor Function Classification System (GMFCS) score if cerebral palsy has been diagnosed
Ensuring that checks of vision and hearing have been carried out in line with national recommendations.

Follow-up and Assessment After 2 Years (Corrected Age)

After the developmental assessment at 2 years (corrected age):

Advise parents or carers of all children that their child should continue to be followed up by universal screening and surveillance services for all children and young people (At the time of publication [August 2017], these universal screening and surveillance services are delivered through the delivered through the Healthy Child Programme in England) and
Advise parents or carers of children born before 28^{+0} weeks' gestation that their child will also be offered a further developmental assessment at 4 years (uncorrected age).

Further Developmental Assessment at 4 Years (Uncorrected Age) for Children Born Before 28^{+0} Weeks' Gestation

Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28^{+0} weeks' gestation that includes as a minimum:

All aspects listed in the first recommendation under "Checks at Each Developmental Visit and Assessment," above
Using the following parent questionnaires, to be completed by parents or carers beforehand and the results discussed during the assessment:
The Strengths and Difficulties Questionnaire (SDQ), to check for social, attentional, emotional and behavioural problems
The Ages and Stages Questionnaire (ASQ) 48-month questionnaire, to check for various aspects of development
Reviewing previous assessments and information from all other relevant sources
Using a standardised test to assess IQ, such as the Wechsler Preschool and Primary Scales of Intelligence 4th Edition (WPPSI) test
GMFCS score if cerebral palsy has been diagnosed
Ensuring that the child has been offered orthoptic vision screening as recommended by the National Screening Committee.

After the 4-year assessment, provide a comprehensive summary of the child's strengths and difficulties, including any developmental problems and disorders, that:

Is in a format that is accessible to parents and carers
If needed, informs the development of a plan for intervention and support, including educational support
Should be shared with the neonatal consultant.

Information Sharing and Referral

If findings at any stage of developmental surveillance, including the assessments at 2 years (corrected age) and 4 years (uncorrected age) (see "Developmental Assessment at 2 Years [Corrected Age]" and "Further Developmental Assessment at 4 Years [Uncorrected Age] for Children Born Before 28^{+0} Weeks' Gestation," below), suggest any developmental problems or disorders:

- Share information with:
  - Parents or carers
  - Primary and secondary healthcare teams
- Refer the child to an appropriate local pathway for further assessment
- Ask parents or carers for permission to share the information with:
  - Education services
  - Social care services as appropriate.

Later Presentation of Learning or Behavioural Problems

Primary and secondary education professionals should be aware that:

- Preterm birth may be a factor in learning or behavioural problems
- These problems can emerge at any point during a child or young person's education
- Prompt referral to educational support services may be needed.

Delivering Enhanced Developmental Support and Surveillance

Enhanced developmental support and surveillance for children born preterm who meet the defined criteria (see "Criteria for Enhanced Developmental Support and Surveillance up to 2 Years [Corrected Age]" and "Criteria for Enhanced Developmental Support and Surveillance up to 4 Years [Uncorrected Age]," above) should:

- Be provided as an integral part of a neonatal service working together with local health services
- Empower parents and carers to be involved in decisions about their child's care
- Be delivered by a multidisciplinary team with the necessary skills (see next recommendation)
- Record outcomes at specified time points for national audit (see "Neonatal Audit," below)
- Be monitored by checking adherence to the recommendations in this guideline, including follow-up rates and outcomes, as part of the routine provision of neonatal care by neonatal operational delivery networks and commissioners.

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include professionals with knowledge and expertise in the following areas:

- Neonatal care
- Development of children born preterm, including developmental problems and disorders (see "Checks at Each Developmental Visit and Assessment," above)
- Providing support in the community, for example for feeding problems
- Administering and interpreting results from questionnaires and standardised tests (for example, the PARCA-R, SDQ, ASQ and IQ tests such as the WPPSI)
- Collating information from a range of sources to facilitate decision-making and writing reports
- Local care pathways, including Early Years education.

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include the following professionals:

- For enhanced developmental support:
  - Neonatologist or paediatrician with an understanding of neonatal care and child development
  - Outreach nurse or nurse with expertise in the development of babies born preterm
- For the surveillance assessments up to and including 2 years (corrected age) (see "Providing Enhanced Developmental Surveillance up to 2 Years [Corrected Age]" above):
  - Neonatologist or paediatrician with an understanding of neonatal care and child development
  - At least one of occupational therapist, physiotherapist and speech and language therapist
- For the surveillance assessment at 4 years (uncorrected age) (see "Further Developmental Assessment at 4 Years [Uncorrected Age] for Children Born Before 28^{+0} Weeks' Gestation):
  - Educational or clinical psychologist
  - Paediatrician with expertise in neurodevelopment.

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should have access to the following professionals:

- Community nurse or health visitor
- Occupational therapist
- Physiotherapist
- Speech and language therapist
- Paediatric neurologist
- Dietitian.

Neonatal Audit

Record the following information, as applicable, in the National Neonatal Research Database for every child born preterm who has enhanced developmental surveillance:

- Whether the child had specialist neonatal care and if so, relevant details
- The reasons for enhanced surveillance (see "Criteria for Enhanced Developmental Support and Surveillance up to 2 Years [Corrected Age]" and "Criteria for Enhanced Developmental Support and Surveillance up to 4 Years [Uncorrected Age]," above)
- At the assessment at 2 years (corrected age) (see "Developmental Assessment at 2 Years [Corrected Age]," above):
  - Diagnosis of cerebral palsy
  - GMFCS score if cerebral palsy is present
  - PARCA-R score
  - Epilepsy that is currently being treated
  - Impairments of hearing, vision, speech and language, and motor skills (as defined in Figure 3 in Classification of health status at 2 years as a perinatal outcome, report of a BAPM/RCPCH working group , version 1.0, 8 January 2008).
- At the assessment at 4 years (uncorrected age) (see "Further Developmental Assessment at 4 Years [Uncorrected Age] for Children Born Before 28^{+0} Weeks' Gestation," above):
  - Diagnosis of cerebral palsy
  - GMFCS score if cerebral palsy is present
  - Full scale IQ score
  - SDQ total difficulty score, subscale scores and impact score
  - Any formal clinical diagnoses of a developmental disorder (for example, autism spectrum disorder)
  - Epilepsy that is currently being treated
  - The presence of a hearing impairment, defined as profound deafness or impairment severe enough to need hearing aids or cochlear implant
  - Results of national orthoptic vision screening.

Record routine educational measures at Key Stage 2 (including special educational needs and disability [SEND]) on an operational delivery network-wide basis, to allow educational outcomes at 11 years to be linked to neonatal information.

Definitions

Strength of Recommendations

Some recommendations can be made with more certainty than others, depending on the quality of the underpinning evidence. The Committee makes a recommendation based on the trade-off between the benefits and harms of a system, process or an intervention, taking into account the quality of the underpinning evidence. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The Committee usually uses 'must' or 'must not' only if there is a legal duty to apply the

recommendation. Occasionally the Committee uses 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The Committee uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, a system, process or an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer…') are used when the Committee is confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The Committee uses 'consider' when confident that a system, process or an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Clinical Algorithm(s)

A National Institute for Health and Care Excellence (NICE) pathway titled "Developmental follow-up of children and young people born preterm overview" is provided on the NICE Web site .

Scope

Disease/Condition(s)

Developmental problems (such as feeding difficulties) and disorders (such as cerebral palsy and autism)

Guideline Category

Evaluation

Management

Clinical Specialty

Family Practice

Neurology

Pediatrics

Psychiatry

Psychology

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Health Care Providers

Health Plans

Nurses

Occupational Therapists

Patients

Physical Therapists

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Public Health Departments

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

To improve the identification of developmental problems and disorders in children born preterm, alert health professionals to risk factors that may increase the likelihood of these problems, define those preterm babies who are eligible for enhanced surveillance and support, and set standards for the delivery of enhanced surveillance and support

Target Population

Babies, children and young people under 18 years who were born preterm (before 37^{+0} weeks of pregnancy)

Interventions and Practices Considered

1. Providing information and support, including on discharge and for ongoing support and follow-up
2. Awareness of risk and prevalence of developmental problems and disorders
3. Enhanced developmental support and surveillance
    - Checks at each developmental visit and assessment
    - Developmental assessment at 2 years (corrected age)
    - Follow-up and assessment after 2 years (corrected age)
    - Further development assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation
    - Information sharing and referral
    - Awareness of later presentation of learning or behavioural problems
4. Delivery of care by multidisciplinary team
5. Neonatal audit

Major Outcomes Considered

- Quality of life (both health- and social-related quality)
- Social functioning
- Ability to carry out activities of daily living
- Educational attainment

- Cost-effectiveness

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Developing the Review Questions and Protocols

The review questions were drafted by the NGA technical team, then refined and validated by the Committee. The questions were based on the key clinical areas identified in the scope (see Appendix A). Literature searches, critical appraisal and synthesis of the evidence was conducted for each review question.

The review framework was determined by the type of question:

Prognostic reviews – population, risk factors and outcomes
Prevalence reviews – population, outcomes/conditions of interest and context
Reviews of diagnostic test accuracy – population, index tests, reference standard and target condition
Qualitative reviews – population, area of interest and outcomes.

A total of 9 review questions were identified (see Table 4 in the full version of the guideline).

Searching for Evidence

Clinical Literature Searches

Systematic literature searches were undertaken to identify all published clinical evidence relevant to each review question.

Databases were searched using medical subject headings, free-text terms and study type filters where appropriate. Where possible, searches were restricted to retrieve articles published in English. All searches were limited by date to 1990 onwards because the change in the use of surfactants at this time significantly altered outcomes in areas covered by the guideline. All searches were conducted in the MEDLINE, EMBASE and Health Technology Assessments (HTA) databases as well as various databases that form parts of The Cochrane Library. All searches were updated on 20th October 2016. Any studies added to the databases after this date (including those published prior to this date but not yet indexed) were not considered relevant for inclusion.

Search strategies were quality assured by cross-checking reference lists of relevant papers, analysing search strategies from other systematic reviews and asking Guideline Committee members to highlight key studies. All search strategies were also quality assured by an Information Scientist who was not

involved in the development of the search. Details of the search strategies, including study type filters that were applied and databases that were searched, can be found in Appendix E.

All references suggested by stakeholders at the time of the scope consultation were considered for inclusion. During the scoping stage, searches were conducted for guidelines, health technology assessments, systematic reviews, economic evaluations and reports on biomedical databases and Web sites of organisations relevant to the topic. Formal searching for grey literature, unpublished literature and electronic, ahead-of-print publications was not routinely undertaken.

Reviewing the Evidence

The process for reviewing the evidence was as follows:

> The titles and abstracts of records retrieved by the literature searches were sifted for relevance, and potentially relevant publications were obtained in full text.
> Full papers were reviewed against inclusion and exclusion criteria in order to identify relevant studies (review protocols are included in Appendix D).

Refer to the "Description of clinical evidence" sections in the full version of the guideline for additional inclusion/exclusion criteria.

Health Economic Literature Searches

Systematic literature searches were also undertaken to identify relevant published health economic evidence. A broad search was conducted to identify evidence relating to developmental follow-up of preterm babies in the following databases: NHS Economic Evaluation Database (NHS EED), HTA, Medline, Cochrane Central Register of Controlled Trials (CCTR) and EMBASE with an economic search filter applied. Where possible, the search was restricted to articles published in English and studies published in languages other than English were not eligible for inclusion.

The search strategies for the health economic literature search are included in Appendix E. All searches were updated on 20th October 2016. Any studies added to the databases after this date (including those published prior to this date but not yet indexed) were not included unless specifically stated in the text.

Evidence of Cost-effectiveness

The health economic evidence presented in the guideline aims to inform the Committee about potential economic issues and ensure that the recommendations represent a cost-effective use of healthcare resources. Health economic evaluations aim to integrate data on benefits (ideally in terms of quality adjusted life years [QALYs]), harms and costs of different care options.

Literature Review

The Health Economist assessed the titles and abstracts of publications identified by the literature searches using the pre-defined eligibility criteria specified in Table 10 in the full version of the guideline.

Number of Source Documents

See Appendix F (see the "Availability of Companion Documents" field) for PRISMA flow charts detailing the study selection process for each review question.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence

High – further research is very unlikely to change confidence in the estimate of effect.

Moderate – further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.

Low – further research is very likely to have an important impact on confidence in the estimate of effect and is likely to change the estimate.

Very low – any estimate of effect is very uncertain.

Methods Used to Analyze the Evidence

Meta-Analysis

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Reviewing and Synthesising the Evidence

The process for reviewing and synthesising the evidence was as follows:

> Relevant studies were critically appraised using the appropriate checklist as specified in the NICE guidelines manual 2014 (see the "Availability of Companion Documents" field). For diagnostic questions the Quality Assessment of Diagnostic Accuracy Studies (QUADAS-2) checklist was used. For prognostic (risk factors) reviews, the quality of the evidence was assessed using the checklist developed and published by Hayden et al. 2013. For prevalence questions, the quality of the evidence was assessed by using the tool developed and published by The Joanna Briggs Institute (The Joanna Briggs Institute, 2014; Munn et al., 2014). For qualitative reviews, a checklist for qualitative based on the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies (http://www.casp-uk.net/casp-tools-checklists) was used.
> Key information was extracted on the study's methods, patient, intervention, comparator, outcome (PICO) factors and results. This is presented in summary tables within each chapter of the guideline and evidence tables (in Appendices K and J).
> Summaries of evidence by outcome were generated and then presented to the Committee for discussion:
>
> > Prognostic (risk) studies – data were presented as measures of association (odds ratios, risk ratios, hazard ratios and adjusted hazard ratios); the decision about whether meta-analysis could be conducted was based on the appraisal of heterogeneity between the studies. In all cases meta-analysis was not considered appropriate.
> > Prevalence studies – data were presented as measures of prevalence or incidence during a period of time (proportions with their 95% confidence intervals); the decision about whether meta-analysis could be conducted was based on the appraisal of heterogeneity between the studies. In all cases meta-analysis was not considered appropriate.
> > Diagnostic/predictive accuracy studies – presented as measures of diagnostic/predictive test accuracy (sensitivity, specificity, positive and negative likelihood ratio); the decision about whether meta-analysis could be conducted was based on the appraisal of heterogeneity

between the studies. In all cases meta-analysis was not considered appropriate.
Qualitative studies – the themes of the studies were organised in a modified version of a GRADE profile, where possible, along with quality assessment otherwise presented in a narrative form.
Delivering enhanced support and surveillance review – narrative summaries of the included literature (including grey literature) were presented.

Double-sifting was done by a second reviewer for a 5% sample of the abstract list for searches prioritised for health economic modelling and those for complex reviews. If discrepancies were observed, they were solved on a one-by-one basis.

Double-data extraction was done by a second reviewer for a 5% sample for a review question that were considered complex in order to assure the quality of the data extraction and minimise potential risk of reviewer bias or error.

Type of Studies

The type(s) of study design considered optimal for inclusion depended on the review question being asked.

For clinical prediction (risk) and diagnostic and prognostic reviews, prospective observational studies of N>50 participants were prioritised for inclusion. This is based on the requirements proposed by Green (1991) which is a sample size greater than or equal to 50 participants plus a minimum of 8 variables or predictors.

For prevalence reviews, the Committee prioritised cross-sectional studies and prospective cohort studies (national registries were preferred) with sample sizes greater than 250 participants. The larger sample size was required for precision.

For qualitative reviews: the Committee prioritised studies that have collected and analysed data qualitatively (for example using interviews, focus groups, surveys and thematic analysis). Studies that only reported quantitative descriptive data were not prioritised for this type of review.

For the review about delivering enhanced support and surveillance, the Committee prioritised randomised controlled trials and observational studies. However, they agreed that in the absence of such evidence, grey literature, including expert opinion papers and published developmental follow-up models should be considered.

Sample size cut-offs were agreed with the Committee at the time of protocol development, due to the methodological considerations outlined below and their knowledge of the published evidence base for each topic.

Please refer to Appendix D for full details on the study design of studies selected for each review question.

Data Synthesis

Prognostic (Risk) and Prevalence Reviews

Study results were presented according to the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-analyses) (see Appendix F). Risk factors that were assessed in a multivariated regression analysis model with adjustment for important confounders were reported. To assist with the ease of interpretation, only results from studies where outcomes were assessed dichotomously were included and reported. Prevalence estimates (proportions) with their 95% confidence intervals were reported or calculated where sufficient data were available. Odds ratios that were adjusted in multivariate analyses for the prespecified confounders were considered the preferred measure.

Studies were categorised according to type of outcome and where data were available, results were reported by subgroups pre-specified in the review protocol. As GRADE is not suitable for this type of review the overall confidence in quality of the evidence was made using the methods described under "Prognostic Outcomes," below.

The appropriateness of meta-analysis was assessed by considering whether there was clinical variation

and/or methodological heterogeneity across studies. Specifically, the following factors were considered:

- Inclusion/exclusion criteria of participants
- Age of participants at time of assessment
- Whether confounders and risk factors were adjusted for in multivariate analysis models
- Whether studies adjusted for the same confounders and risk factors in multivariate analyses
- How outcomes are defined
- Measurement tools and scales for the assessment of outcomes
- Consistency of results

Risk factors were also presented graphically in forest plots (Appendix J). The forest plots displayed all the evidence assessing the association between a risk factor and an outcome as odds ratios.

Prevalence estimates were also presented graphically by outcomes in forest plots (Appendix J). The forest plots displayed all studies that assessed the prevalence and an estimate of the prevalence of that outcome in the sample is presented as a percentage with 95% confidence intervals (CIs). The forest plots for prevalence were presented in a non-logarithmic scale for better visual presentation.

The forest plots for both risk and prevalence evidence were organised by outcome where evidence allowed and in presence of a lot of evidence for an outcome also by gestational age group specified in the review protocols. The forest plots were generated using the statistical software STATA.

Diagnostic Test Accuracy Reviews

For studies assessing the diagnostic accuracy of screening tools (index test) compared to diagnostic tests (reference standard) the following outcomes were considered:

- Sensitivity
- Specificity
- Positive likelihood ratio (LR+)
- Negative likelihood ratio (LR-).

These diagnostic accuracy parameters (with 95% CI) were obtained from the studies or calculated by the technical team using data from the studies (see Table 5 in the full version of the guideline).

The following definitions were used when summarising the levels of sensitivity or specificity for the Committee:

- High: 90% and above
- Moderate: 75% to 89%
- Low: 74% or below

The following definitions were used when summarising the likelihood ratios for the Committee:

- Very useful test: LR+ higher than 10, LR- lower than 0.1
- Moderately useful test: LR+ 5 to 10, LR- 0.1 to 0.2
- Not a useful test: LR+ lower than 5, LR- higher than 0.2

Qualitative Reviews

A thematic approach was used to identify concepts across qualitative studies. Where possible, a meta-synthesis was conducted to combine results. Themes or new perspectives of a particular topic from the studies were extracted and the characteristics summarised. Common concepts were categorised and tabulated including how many studies contributed to an overarching theme. Sampling of studies continued until no new relevant qualitative data emerged known as 'theoretical saturation' (Dixon-Wood, 2005). A final selection of included studies was agreed between two reviewers. Themes from the individual studies were categorised into overarching categories of themes with sub-themes. Themes were derived from direct quotes from individual studies by those who were interviewed. A thematic map was then developed to demonstrate the relationship between themes and subthemes.

Appraising the Quality of Evidence

Prognostic Outcomes

Quality of prognostic studies and evidence was assessed using the checklist created by Hayden et al. (2013).

This risk of bias for each risk factor across studies was derived by assessing the risk of bias across 6 domains for each study: study participation, study attrition, prognostic factor measurement, outcome measurement, study confounding, and statistical analysis and reporting, with the last 4 domains being assessed for each outcome. More details about the quality assessment for prognostic studies are shown in Table 6. The assessment of the overall quality of the evidence was based on the reviewer's judgment considering the assessment of all the 6 domains. For example, if there was a high risk of bias in any domain, the evidence was considered to be of low quality; if there was moderate risk of bias as defined by Hayden et al. (2013) in some of the domains, the evidence was considered to be moderate quality; and if there was low risk of bias in all domains, the evidence was considered to be of high quality.

Prevalence Outcomes

Quality of prevalence outcomes was assessed using the checklist created by The Joanna Briggs Institute (The Joanna Briggs Institute, 2014; Munn et al., 2014).

The quality was assessed based on answering 'yes', 'no', 'unclear', or 'not applicable' to the following questions:

Was the sample representative of the target population?
Were the study participants recruited in an appropriate way?
Was the sample size adequate?
Were the study subjects and setting described in detail?
Is the data analysis conducted with sufficient coverage of the identified sample?
Were objective, standard criteria used for measurement of the condition?
Was the condition measured reliably?
Was there appropriate statistical analysis?
Are all important confounding factors/subgroups/differences identified and accounted for?
Were subpopulations identified using objective criteria?

The assessment of the overall quality of the evidence was based on the reviewer's judgment considering the answers to the questions above. For example, if there were several 'no' and 'unclear' answers, the quality of the evidence was considered to be low or very low; if there were some 'unclear' answers the quality of the evidence was considered to be moderate; and if all answers for the above questions were 'yes' or did not raise concern, the evidence was considered to be of high quality.

Diagnostic Outcomes

For diagnostic accuracy studies, the Quality Assessment of Diagnostic Accuracy Studies version 2 (QUADAS-2) checklist was used to assess risk of bias and applicability of the evidence (Whiting et al., 2011). The assessment of risk of bias and applicability of patient selection, index test, reference standard and flow and timing were done. More details of the QUADAS-2 is given in Table 7.

For the assessment of the overall quality of the diagnostic accuracy evidence, adapted GRADE methodology was used. At the time of writing, the GRADE methodology, as developed by the international GRADE working group, was available for RCTs and observational studies only. The Committee adapted the quality assessment elements and outcome presentation for diagnostic accuracy studies. GRADE methodology takes into account the assessment of 5 different domains: risk of bias, inconsistency, indirectness, imprecision, and publication bias. Note that publication bias was not systematically considered in this guideline. Table 8 in the full version of the guideline gives more details of the different domains. The assessment of risk of bias and indirectness were based on the QUADAS-2 assessment described above.

The overall quality of the diagnostic accuracy evidence was based on the sum of the grading of the different domains of GRADE. Inconsistency was not considered applicable when no meta-analysis was performed. The reasons or criteria used for downgrading were specified in the footnotes of the adapted GRADE tables.

Qualitative Studies

The main quality assessment domains are organised across the definition of population included, the appropriateness of methods used and the completeness of data analysis and the overall relevance of the study participants to the population of interest for the guideline.

Individual studies were assessed for methodological limitations using an adapted CASP (2013) checklist for qualitative studies, where items in the original CASP checklist were adapted and fitted into 5 main quality appraisal areas according to the following criteria:

Aim (description of aims and appropriateness of the study design)
Sample (clear description, role of the researcher, data saturation, critical review of the researchers' influence on the data collection)
Rigour of data selection (method of selection, independence of participants from the researchers, appropriateness of participants)
Data collection analysis (clear description, how are categories or themes derived, sufficiency of presented findings, saturation in terms of analysis, the role of the researcher in the analysis, validation)
Results /findings (clearly described, applicable and comprehensible, theory production)

An adapted GRADE-CERQual (Lewin, 2015) approach was used to present and summarise qualitative findings across studies. This approach considers the quality of evidence by themes. Themes may have originated from an individual study or been identified through a number of individual themes or components of themes from a number of included studies. Quality is assessed in the domains described in Table 9 in the full version of the guideline.

Evidence Statements

Evidence statements are statements that summarise the key features of the clinical evidence presented. The wording of the evidence statements reflects the amount of certainty in the estimate of effect. They are presented by comparison (for interventional reviews) or by description of outcome where appropriate and encompass the following key features of the evidence:

The number of studies and the number of participants for a particular outcome
A brief description of the participants
An indication of the direction of effect (if 1 treatment is beneficial or harmful compared with the other, or whether there is no difference between the 2 tested treatments)
A description of the overall quality of evidence.

Evidence of Cost-effectiveness

Literature Review

Once the screening of titles and abstracts was complete, full versions of the selected papers were obtained for assessment. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) for this search on economic evaluations is presented in Appendix F.

As well as reviewing the published economic literature, as described above, new economic analysis was undertaken in selected areas prioritised by the Committee in conjunction with the health economist. Topics were prioritised on the basis of the following criteria, in accordance with the NICE guidelines manual:

The overall importance of the recommendation, which may be a function of the number of patients affected and the potential impact on costs and health outcomes per patient

The current extent of uncertainty over cost-effectiveness, and the likelihood that economic analysis will reduce this uncertainty
The feasibility of building an economic model

The following priority areas for de novo economic analysis were agreed by the Committee after formation of the review questions and consideration of the available health economic evidence:

Screening strategies for the identification of children and young people born preterm with intellectual disability, speech and language disorder and specific leaning difficulty
Delivery of enhanced support and surveillance

The methods and results of de novo economic analyses are reported in Appendix H. When new economic analysis was not prioritised, the Committee made a qualitative judgement regarding cost effectiveness by considering expected differences in resource and cost use between options, alongside clinical effectiveness evidence identified from the clinical evidence review.

Cost-effectiveness Criteria

NICE's report Social value judgements: principles for the development of NICE guidance sets out the principles that Committees should consider when judging whether an intervention offers good value for money. In general, an intervention was considered to be cost effective if either of the following criteria applied (given that the estimate was considered plausible):

The intervention dominated other relevant strategies (that is, it was both less costly in terms of resource use and more clinically effective compared with all the other relevant alternative strategies), or;
The intervention cost less than £20,000 per QALY gained compared with the next best strategy, or;
The intervention provided clinically significant benefits at an acceptable additional cost when compared with the next best strategy.

The Committee's considerations of cost-effectiveness are discussed explicitly in the 'Consideration of economic benefits and harms' section for each topic.

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Who Developed This Guideline?

A multidisciplinary guideline Committee comprising healthcare professionals and researchers as well as lay members developed this guideline.

The Committee met every 4 to 6 weeks during the development of the guideline. Staff from the NGA provided methodological support and guidance for the development process. The team working on the guideline included a guideline lead, project manager, systematic reviewers, health economists and information scientists. They undertook systematic searches of the literature, appraised the evidence, conducted data analysis and cost-effectiveness analysis (where appropriate) and drafted the guideline in collaboration with the Committee.

Developing Recommendations

Over the course of the guideline development process, the Committee was presented with:

- Evidence tables of the clinical and economic evidence reviewed from the literature (see Appendices H, I, and K)
- Summary of clinical and economic evidence and quality assessment
- Forest plots (Appendix J)
- A description of the methods and results of the cost-effectiveness analysis undertaken for the guideline (Appendices H and I).

Recommendations were drafted on the basis of the Committee's interpretation of the available evidence, taking into account the balance of benefits, harms and costs between different courses of action. Firstly, the net benefit over harm (clinical effectiveness) was considered, focusing on the critical outcomes, although most of the reviews in the guideline were outcome driven. The Committee took into account the clinical benefits and harms when one intervention was compared with another. The assessment of net benefit was moderated by the importance placed on the outcomes (the Committee's values and preferences), and the confidence the Committee had in the evidence (evidence quality). Secondly, the Committee assessed whether the net benefit justified any differences in costs.

When clinical and economic evidence was of poor quality, conflicting or absent, the Committee drafted recommendations based on their expert opinion. The considerations for making consensus-based recommendations include the balance between potential harms and benefits, the economic costs or implications compared with the economic benefits, current practices, recommendations made in other relevant guidelines, patient preferences and equality issues. The Committee also considered whether the uncertainty was sufficient to justify delaying making a recommendation to await further research, taking into account the potential harm of failing to make a clear recommendation.

The wording of recommendations was agreed by the Committee and focused on the following factors:

- The actions healthcare professionals need to take
- The information readers need to know
- The strength of the recommendation (for example the word 'offer' was used for strong recommendations and 'consider' for weak recommendations)
- The involvement of parents, carers and families in decisions about treatment and care
- Consistency with NICE's standard advice on recommendations about drugs, waiting times and ineffective intervention.

The main considerations specific to each recommendation are outlined in the 'Recommendations and link to evidence' sections within each section.

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

Some recommendations can be made with more certainty than others, depending on the quality of the underpinning evidence. The Committee makes a recommendation based on the trade-off between the benefits and harms of a system, process or an intervention, taking into account the quality of the underpinning evidence. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The Committee usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally the Committee uses 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The Committee uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast

majority of people, a system, process or an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer…') are used when the Committee is confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The Committee uses 'consider' when confident that a system, process or an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Cost Analysis

Refer to the health economic evidence statements in the full version of the guideline (see the "Availability of Companion Documents" field) for a discussion of published economic evidence for each of the guideline review questions. The full health economics report is provided in Appendix H.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Validation Process

This guidance is subject to a 6-week public consultation and feedback as part of the quality assurance and peer review of the document. All comments received from registered stakeholders receive individual responses that are posted on the National Institute for Health and Care Excellence (NICE) Web site when the pre-publication check of the full guideline occurs.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

Refer to the "Evidence to recommendations" sections in the full version of the guideline for detailed discussion of the evidence supporting each recommendation. Also refer to Appendix D for full details on the study design of studies selected for each review question.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

- Knowledge of risk factors for different development disorders and problems enables health care professionals to effectively identify babies and children born prematurely who are more likely to

experience a developmental disorder or problems, and prioritise surveillance services accordingly.

- Social, attentional, emotional and behavioural problems in children born preterm may go unnoticed, yet can have an adverse impact on a child's health and wellbeing, quality of life and school performance, as well as on their family. Identifying children at risk of these problems will enable appropriate intervention and family support to be provided in order to reduce their impact. In particular, identifying problems before school entry will support education planning and promote social and emotional development and attainment at school.
- Children born before 28 weeks' gestation are at risk for cognitive deficits which may have an adverse impact on their learning and achievement at school. Learning difficulties may become apparent or exacerbated during early childhood as schooling places increasing cognitive demands on the child. Performing a cognitive assessment at 4 age years, prior to school entry can be used to inform parents of their child's risk for learning difficulties in order that support can be put in place from the outset of schooling.
- Identification of speech, language and communication problems at 2 years (corrected age) may allow early intervention that will help children when they move into early years education, as well as during their school years. It may also help to prevent other problems in the future, such as mental health problems and conduct disorders.
- Enhanced developmental support and surveillance up to age 4 years (uncorrected age) for children born preterm who fulfil the necessary criteria is expected to increase the detection of developmental problems and disorders and improve outcomes for these children.
- The engagement and involvement of parents and carers improves outcomes for the child and because providing information reduces confusion and unnecessary stress and anxiety among parents and carers, which in turn can also improve the outcomes for the child.

Refer to the "Consideration of clinical benefits and harms" sections of the full version of the guideline (see the "Availability of Companion Documents" field) for details about benefits of specific interventions.

Potential Harms

False positive and false-negative results of evaluations

Refer to the "Consideration of clinical benefits and harms" sections of the full version of the guideline (see the "Availability of Companion Documents" field) for details about potential harms of specific interventions.

Qualifying Statements

Qualifying Statements

- The recommendations in this guideline represent the view of the National Institute for Health and Care Excellence (NICE), arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.
- Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.
- Commissioners and providers have a responsibility to promote an environmentally sustainable health

and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Implementation of the Guideline

Description of Implementation Strategy

Putting This Guideline into Practice

The National Institute for Health and Care Excellence (NICE) has produced tools and resources to help put this guideline into practice (see also the "Availability of Companion Documents" field).

One issue was highlighted that might need specific thought when implementing the recommendations. This was raised during the development of this guideline. The issue is service organisation for implementing the developmental assessment at 4 years (uncorrected age).

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

- Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations.
- Identify things staff can include in their own practice straight away.
- Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
- Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.
- Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
- Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
- For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.
- Implement the action plan with oversight from the lead and the project group. Big projects may also

need project management support.
Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See the into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Implementation Tools

Clinical Algorithm

Patient Resources

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

National Guideline Alliance. Developmental follow-up of children and young people born preterm. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. 29 p. (NICE guideline; no. 72).

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2017 Aug 9

Guideline Developer(s)

National Guideline Alliance - National Government Agency [Non-U.S.]

Source(s) of Funding

The National Guideline Alliance (NGA) was commissioned by the National Institute for Health and Care Excellence (NICE) to undertake the work on this guideline.

Guideline Committee

Guideline Committee

Composition of Group That Authored the Guideline

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Financial Disclosures/Conflicts of Interest

At the start of the development process all group members were required to declare interests including consultancies, fee-paid work, shareholdings, fellowships and support from the healthcare industry in accordance with the National Institute of Health and Care Excellence (NICE) policy on Conflicts of Interest . At all subsequent group meetings, members declared all subsequent potential conflicts of interest.

Members were either required to withdraw completely or for part of the discussion if their declared interest made it appropriate. The details of declared interests and the actions taken are shown in Appendix C (see the "Availability of Companion Documents" field).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Available from the National Institute for Health and Care Excellence Web site .

Also available for download in eBook and ePub formats from the NICE Web site .

Availability of Companion Documents

The following are available:

Developmental follow-up of children and young people born preterm. Full guideline. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. 668 p. (NICE guideline; no. 72). Available from the National Institute for Health and Care Excellence (NICE) Web site .

Developmental follow-up of children and young people born preterm. Appendices. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. (NICE guideline; no. 72). Available from the NICE Web site .

Developmental follow-up of children and young people born preterm. Baseline assessment tool. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. (NICE guideline; no. 72). Available from the NICE Web site .

Developmental follow-up of children and young people born preterm. Resource impact statement. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. (NICE guideline; no. 72). Available from the NICE Web site .

The guidelines manual. London (UK): National Institute for Health and Care Excellence (NICE); 2012 Nov. Available from the NICE Web site .

Developing NICE guidelines: the manual. London (UK): National Institute for Health and Care Excellence (NICE); 2014 Oct. Available from the NICE Web site .

Patient Resources

The following is available:

Developmental follow-up of children and young people born preterm. Information for the public. London (UK): National Institute for Health and Care Excellence (NICE); 2017 Aug 9. 29 p. (NICE guideline; no. 72). Available from the National Institute for Health and Care Excellence (NICE) Web site .

NGC Status

This NGC summary was completed by ECRI Institute on August 29, 2017. The guideline developer agreed to not review the content.

This NEATS assessment was completed by ECRI Institute on August 23, 2017. The information was verified by the guideline developer on September 26, 2017.

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